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Abstract

Living-donor kidney and liver transplantation intend to improve pediatric recipients' psychosocial well-being, but psychosocial impact in recipients strongly depends upon the impact on the donor and the quality of family relations. We systematically reviewed quantitative and qualitative studies addressing the psychosocial impact of pediatric living-donor kidney and liver transplantation in recipients, donors, and the family. In accordance with the PRISMA guidelines, we systematically searched the databases Medline, Web of Knowledge, Cinahl, Embase, ERIC, and Google Scholar. We identified 23 studies that satisfied our inclusion criteria. Recipients had improved coping skills and satisfactory peer relationships, but also reported anxiety and depressive symptoms, worried about the future, and had a negative body image. Similarly, donors experienced increased self-esteem, empowerment, and community awareness, but also complained of postoperative pain and a lack of emotional support. With...

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REVIEW

Psychosocial impact of pediatric living-donor kidney and liver transplantation on recipients, donors, and the family: a systematic review

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Keywords

family, kidney transplantation, liver transplantation, living-donor transplantation, psychosocial impact, systematic review.

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Summary

Living-donor kidney and liver transplantation intend to improve pediatric recipients' psychosocial well-being, but psychosocial impact in recipients strongly depends upon the impact on the donor and the quality of family relations. We systematically reviewed quantitative and qualitative studies addressing the psychosocial impact of pediatric living-donor kidney and liver transplantation in recipients, donors, and the family. In accordance with the PRISMA guidelines, we systematically searched the databases Medline, Web of Knowledge, Cinahl, Embase, ERIC, and Google Scholar. We identified 23 studies that satisfied our inclusion criteria. Recipients had improved coping skills and satisfactory peer relationships, but also reported anxiety and depressive symptoms, worried about the future, and had a negative body image. Similarly, donors experienced increased self-esteem, empowerment, and community awareness, but also complained of postoperative pain and a lack of emotional support. With respect to family impact, transplantation generated a special bond between the donor and the recipient, characterized by gratitude and admiration, but also raised new expectations concerning the recipient's lifestyle. As psychological problems in recipients were sometimes induced by feelings of guilt and indebtedness toward the donor, we recommend more research on how gift exchange dynamics function within donor-recipient relationships, enrolling donors and recipients within the same study.

Introduction

Living-donor kidney and liver transplantation are increasingly accepted alternatives to deceased-donor transplantation in children, offering several benefits (shorter waiting times, reduced ischemia time, and more thorough donor screening) which contribute to superior graft and patient outcomes [1–3]. Transplantation, though, not only intends to successfully restore children's physical health, but also to

improve their social and psychological well-being [4]. Psychosocial impact in pediatric recipients is strongly interrelated with the impact on the family as a unit. For instance, if the child's caregivers experience psychological difficulties or distress, or if family relations are characterized by many conflicts or high levels of parental protectiveness over the child, this is likely to have a negative impact on the recipient's psychological response to the transplantation [5–7].

However, it remains uncertain how recipient outcomes and family relations are affected if the child is transplanted with a living donor within the family. In this respect, reference may be made to Marcel Mauss' theory of the gift [8], which identifies three complementary obligations within the gift exchange process: to give, to receive, and to give in return (to reciprocate). As this theory is sometimes referred to in order to better understand the transplantation process, we shall analyze those obligations in more detail. First, the process starts with an obligation to give, which is often perceived as a 'straightforward' decision, especially in pediatric transplantation. Indeed, many parents consider their decision to donate as a natural consequence of the responsibility to take care for their children [9]. Second, the recipient must be able to accept the organ, which also implies the acknowledgement of a special relationship between himself and the donor. Many recipients therefore find it emotionally burdensome to accept the organ, and their decision-making process might be more difficult than that of donors [10]. Third, living-donor transplantation involves an obligation to give something back in return, especially because organ donation is considered to be a very personalized gift which even carries a part of the donor's identity. This obligation to 'give back' may manifest itself in several ways, for instance by being grateful toward the donor, being responsible for one's health, or even by taking good care of one's children, similarly as one has been cared for by one's own parents. By means of reciprocity, recipients might feel able to move ahead with their own lives, without feeling indebted toward the donor [11].

These gift dynamics have so far been studied in a few publications, which pointed out how individual outcomes in donors and recipients depended on the ability to reciprocate. Indeed, although most donors and recipients were satisfied with the transplantation and felt that their relationship had either improved or remained stable [12–14], some recipients were overwhelmed and felt unable to ever return the gift to the donor, resulting in feelings of guilt and indebtedness [15]. Conversely, some donors felt disappointed when recipients were not sufficiently looking after their health, as they were concerned about graft failure [12].

Unfortunately, though, gift dynamics have received far less attention in pediatric transplantation [16]. We are aware of one systematic review which identified an overall improved relationship between adolescent recipients and their donors. However, some adolescents perceived an obligation of gratitude toward the donor and were concerned about the donor's potential degree of control over their lives [6]. However, the donor–recipient relationship was exclusively studied from the recipient's point of view and only adolescent recipients were targeted, whereas children who were younger at study time were not included.

Indeed, it is often believed that the younger the child at the time of transplant, the less he is aware of its implications on the donor–recipient relationship. Consequently, parents and healthcare professionals might think that there is no need to worry about potential adverse psychological consequences which are related to gift dynamics. However, even if a child might be not fully aware of these implications at the time of transplant, we hypothesize that disturbed gift exchange dynamics may have implications later in life and potentially result in a significant disruption of psychological development in the recipient, especially during adolescence. Specifically, a compromised relationship with the donor (usually a parent), characterized by feelings of guilt and indebtedness, might interfere with adolescents' separation–individuation, a psychological process through which a child gradually becomes more independent from his parents on functional and emotional domains and forms his own identity. If this process is compromised, this may likely also make them more dependent upon their family to address their healthcare needs. Indeed, overwhelming feelings of indebtedness have been associated with problems in adhering to one's medication regime [16,17]. This might explain why some studies identified living donation as a risk factor for poor adherence in pediatric transplant recipients [18].

Consequently, psychosocial impact in pediatric transplant recipients can only be adequately understood when investigated in conjunction with the impact on the donor, as well as the impact on family relations. Therefore, we conducted a systematic review of qualitative and quantitative studies to investigate the psychosocial impact of living-donor kidney and liver transplantation on recipients, donors, as well as family relations.

Methods

Data sources

Following the PRISMA guidelines [19], we searched the databases Medline, Web of Knowledge, Cinahl, Embase, and ERIC until April 1, 2014, using standardized search strings (Table 1). Afterwards, we identified articles which were related to, citing or cited by the retrieved articles, by screening their reference lists and consulting the search engine Google Scholar.

Study selection

We included peer-reviewed studies if they (i) used a quantitative and/or qualitative methodology, (ii) addressed the psychosocial impact of pediatric living-donor kidney or liver transplantation on the donor, the recipient, or the family, and (iii) the donor was genetically or emotionally related to the recipient. We defined

Table 1. Overview of search strings.

Database	Search string
Medline	(paediatric [mh] OR adolescence [mh] OR infant [mh] OR pediatric OR paediatric OR adolescent OR adolescents OR adolescence OR child OR children OR childhood OR minors OR young OR infant OR infants OR infancy) AND (living donors [mh] OR donor OR donors OR donation) AND (kidney OR renal OR liver OR hepatic OR kidney transplantation [mh] OR liver transplantation [mh]) AND (quality of life [mh] OR family [mh] OR psychiatry and psychology category [mh] OR psychological OR psychosocial OR social OR emotional OR mental OR quality of life OR family OR adjustment OR cope OR coping)
Embase	('child'/exp OR 'adolescence'/exp OR pediatric OR paediatric OR adolescent OR adolescents OR adolescence OR child OR children OR childhood OR minors OR young OR infant OR infants OR infancy) AND ('living donor'/exp OR donor OR donors OR donation) AND (kidney OR renal OR liver OR hepatic) AND ('quality of life'/exp OR 'psychology'/exp OR 'family relation'/exp OR psychological OR psychosocial OR social OR emotional OR mental OR quality of life OR family OR adjustment OR cope OR coping)
Web of knowledge	(pediatric OR paediatric OR adolescent OR adolescents OR adolescence OR child OR children OR childhood OR minors OR young OR infant OR infants OR infancy) AND (donor OR donors OR donation) AND (kidney OR renal OR liver OR hepatic) AND (psychological OR psychosocial OR social OR emotional OR mental OR quality of life OR family OR adjustment OR cope OR coping)
Cinahl	(pediatric OR paediatric OR adolescent OR adolescents OR adolescence OR child OR children OR childhood OR minors OR young OR infant OR infants OR infancy) AND (donor OR donors OR donation) AND (kidney OR renal OR liver OR hepatic)
ERIC	(pediatric OR paediatric OR adolescent OR adolescents OR adolescence OR child OR children OR childhood OR minors OR young OR infant OR infants OR infancy) AND (donor OR donors OR donation) AND (kidney OR renal OR liver OR hepatic)

a pediatric recipient as being <18 years at the time of transplant, independent of age at study time. Studies which included both living- and deceased-donor transplant recipients were included only if separate results were provided for both groups. We excluded (i) systematic reviews, conference abstracts, letters, editorials, and (ii) studies written in a language other than English, French, German, Dutch, Spanish, or Italian.

Titles and abstracts, as well as full texts of potentially relevant articles, were screened independently by two coauthors. In case of disagreement, a third author was consulted.

Quality of reporting

Quality of reporting was independently assessed by two coauthors. We used a protocol designed by Kmet *et al.* [20], containing separate scoring lists for quantitative and qualitative studies. These included fourteen and ten items, respectively, that were rated as 'yes' (=2), 'partial' (=1), 'no' (=0), or 'not applicable'. Each study was assigned a summary score between 0 and 1 (with higher scores indicating better quality of reporting) by adding the scores of all individual items which were relevant to score, and dividing by the maximum possible score (20 for qualitative and mixed-methods studies, 28 for quantitative studies and case series, depending on the number of items that were relevant to score). Item and summary scores of both authors were compared, and inter-rater agreement was calculated using weighted kappa. If an item was scored differently, a consensus score was given after thorough discussion or, in case of

persisting disagreement, by consulting a third author. The summary scores were intended as indicative and were not part of the selection process.

Data analysis

From each study, the following characteristics were extracted independently by two coauthors: organ type (kidney/liver/both), study participants (donor/recipient/both), data collection methods (qualitative, quantitative, or mixed methods), study context, timing of assessment, and recipient age at the time of transplantation.

As our aim was exploratory rather than confirmatory and a recent systematic review pointed to a lack of operational definition of the concept 'psychosocial' in the context of living organ donation [21], we did not use an *a priori* defined framework to analyze the data. We used an inductive approach instead, extracting the indicators that studies reported themselves to evaluate psychosocial impact. We included indicators that were predetermined by the study authors, as well as indicators that authors identified inductively from qualitative data. As concerns impact on donors and recipients, a list of approximately thirty indicators emerged (Fig. 1). After thorough discussion between the authors, these were organized into three categories: (i) mental health disorders, (ii) emotional and behavioral well-being, and (iii) social functioning. As far as the family was concerned, results were organized according to relationship type: impact on relation between (i) donor and recipient, (ii) donor and nondonor parent, and (iii) donor and other siblings.

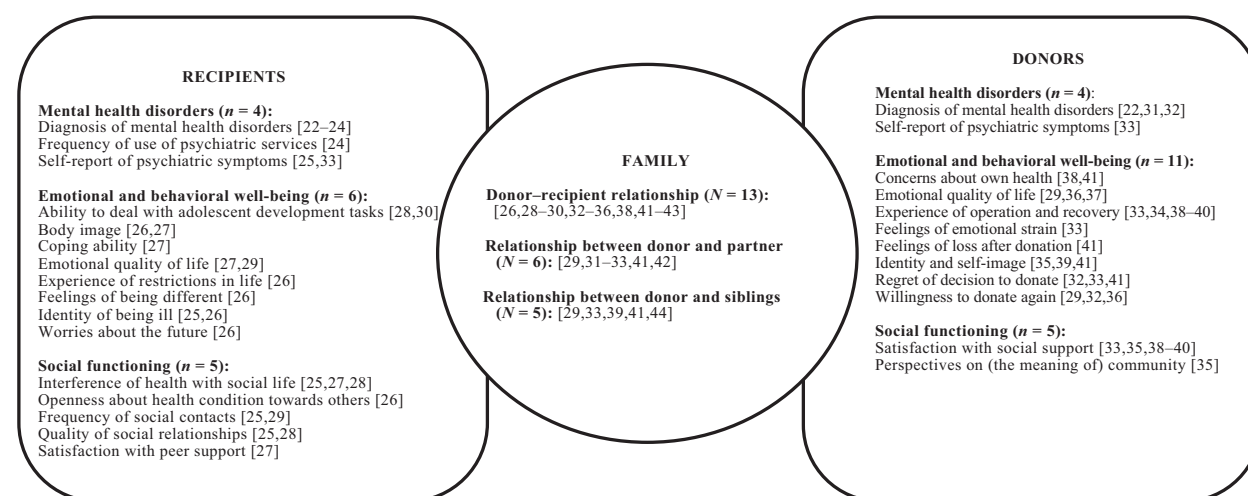


Figure 1 Indicators used to evaluate psychosocial impact in donors, recipients, and the family.

Results

Study characteristics

We identified 23 relevant studies (Fig. 2), of which ten focused on kidney (43%), eleven on liver (48%), and two on both (9%) (Table 2). They were published between 1976 and 2014. Most stemmed from Europe (43%) or North America (36%). Most exclusively included donors (35%) or recipients (35%), whereas only three studies included both (13%) and four also targeted nondonor parents (17%). Eleven studies used quantitative methods (48%), eight qualitative methods (35%), and four a mixed-method approach (17%). Eight studies (35%) exclusively assessed short-term outcomes of transplantation (0–5 years), whereas only three (13%) assessed impact after more than ten years. Of thirteen studies (57%) reporting recipient age at the time of transplant, four exclusively focused on children and seven included both children and adolescents.

Quality of reporting

Quality assessment scores ranged between 0.35 and 0.80 for qualitative and mixed-method studies (mean 0.66; Fig. 3) and between 0.13 and 1.00 for quantitative studies and descriptive case series (mean 0.64; Fig. 4), with higher scores indicating higher quality of reporting. Weighted kappa scores were 0.718 and 0.695, respectively, indicating good inter-rater agreement.

Psychosocial impact on donors, recipients, and family

Living-donor kidney and liver transplantation impacted both favorably, as well as unfavorably, on recipients, donors, and the family.

Impact on recipients

Mental health disorders ($n = 4$): One study reported a low prevalence of mental illness within the first three years after transplantation (3%) [22]. Other studies, though, observed a higher prevalence (62–75%), mainly mood disorders and anxiety disorders [23–25].

Emotional and behavioral well-being ($n = 6$): Most recipients were satisfied with life (58–66%) [25], experienced no emotional restrictions (67%) [26], and did not characterize themselves as being ill (47–67%) [25,26]. In one study, recipients experienced increased self-esteem and a renewed ability to cope with physical, emotional and social stress [27]. However, unfavorable impacts were also reported, including feelings of shame and a fragile body image [27,28], worries about the future (87%), and feelings of ‘being different’ (53%) [26]. In three studies, emotional difficulties and distress in recipients were related to feelings of guilt toward the donor [28–30].

Social functioning ($n = 5$): Most recipients had moderately to completely satisfactory peer relationships [25,27], which increased postoperatively [29]. Conversations and leisure activities with peers often helped to overcome emotional difficulties and to maintain social relationships [27]. In one study, 73% of recipients were at least to some extent willing to discuss their medical condition among peers [26]. Although one study concluded that health status seldom or never interfered with social life [25], others reported some social life restrictions, for instance withdrawal from peers [28] or having to leave parties earlier [27].

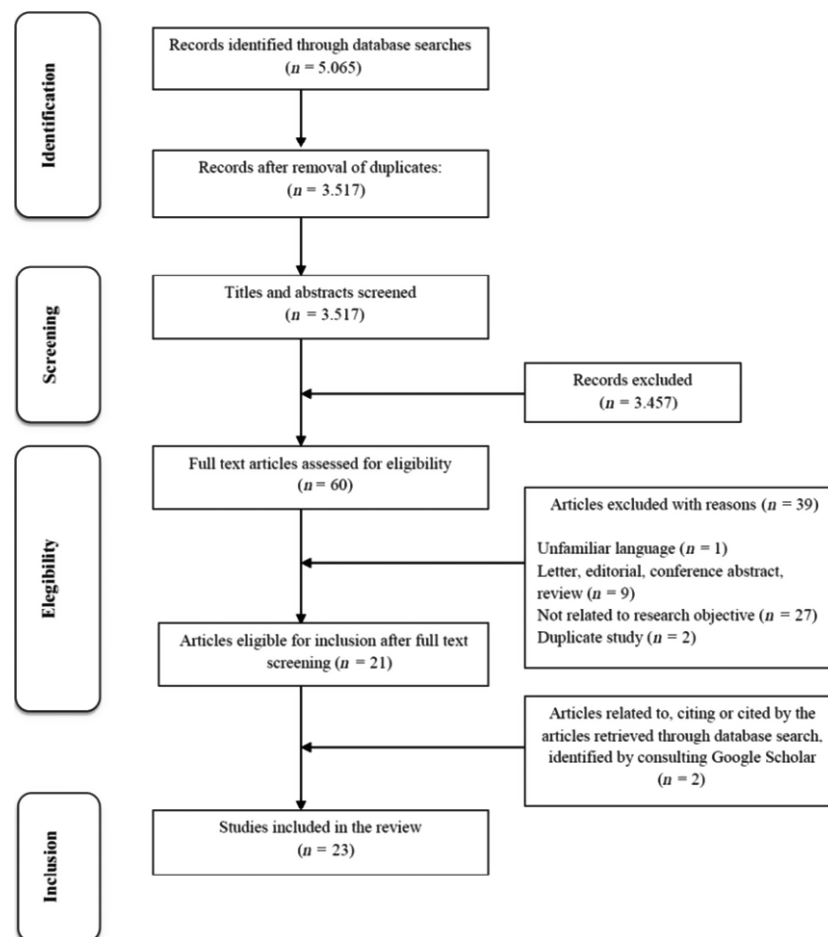


Figure 2 Flow diagram of electronic database searches.

Impact on donors

Mental health disorders (n = 4): In two studies, mental disorders were seldom observed within the first year after donation (1% and 0%, respectively), even if donors experienced some psychological difficulties before donation [22,31].

In another study, by contrast, 12.5% of donors suffered from lowered mood, 6.3% from major depression, and 6.3% from an anxiety disorder, although the criteria on which diagnoses were made were not reported. The presence of these disorders strongly correlated with medical outcomes in the recipient [32]. Similarly, yet another study revealed that 26% of donors experienced some psychosomatic or psychiatric symptoms after the operation [33].

Emotional and behavioral well-being (n = 11): Three studies reported beneficial psychological consequences of donation. In one study, one-third of donors felt more

satisfied after donation [33]. In another, all donors experienced increased self-esteem because of the improved health of the child [34]. Furthermore, living donation empowered donors by allowing them to control the timing of the transplantation and led to an identity shift, for instance by making them more compassionate toward other people [35].

Most donors rated the emotional impact of donation as low (69–90%) [29,36], and emotional quality of life was higher than norm population values [36,37]. In one study, though, over 70% experienced some emotional strain after transplantation [33]. Moreover, several donors complained of more postoperative pain than expected [32,33,36,38–41], and some mentioned it took them a long time to overcome their ‘crisis mode’ level of functioning [40].

Only a minority of donors regretted their decision [32,33,41], and all donors would donate again if necessary [29,32,36]. In one study, though, 63% indicated they would prefer a deceased donor if possible [41], although motivations for doing so were not addressed.

Table 2. Overview of study characteristics.

Characteristic	N (%)	References
Organ type		
Kidney	10 (43)	[24–28,30,33,34,41,42]
Liver	11 (48)	[29,31,32,35–40,43,44]
Kidney and liver	2 (9)	[22,23]
Study participants		
Donors only	8 (35)	[31,32,35–40]
Recipients only	8 (35)	[23–25,27,28,30,34,43]
Donors and recipients	2 (9)	[22,42]
Donor and nondonor parents	4 (17)	[33,34,41,44]
Donors, recipients, and nondonor parents	1 (4)	[29]
Data collection		
Quantitative approach	11 (48)	[22–25,29,32,33,36,37,41,44]
Interviews	1	
Medical record analysis	1	
Generic questionnaires*	2	
Transplant-specific questionnaires†	3	
Projective psychological test	1	
Combination of methods	3	
Qualitative approach	8 (35)	[28,30,34,35,39,40,42,43]
Interviews	6	
Case reports	2	
Mixed quantitative and qualitative approach	4 (17)	[26,27,31,38]
Study context		
Europe	10 (43)	[26,29,32–34,36,37,40–42]
Germany	3	
Sweden	4	
Switzerland	1	
Turkey	1	
United Kingdom	1	
North America/Canada	8 (36)	[24,28,30,31,35,38,39,43]
Asia (Japan)	3 (13)	[22,23,44]
South America (Brazil)	1 (4)	[27]
Africa (Egypt)	1 (4)	[25]
Recipient age at time of transplantation		
Children only (0–11 years)	4 (17)	[36,38,39,44]
Adolescents only (12–18 years)	2 (9)	[28,30]
Children and adolescents (0–18 years)	7 (31)	[25,33–35,40,41]
Not specified	10 (43)	[22–24,27,29,31,32,37,42,43]
Maximal time interval between transplantation and assessment		
<1 year	1 (5)	[31]
1–5 years	7 (30)	[22,28,30,34,37,38,44]
6–10 years	7 (30)	[32,33,36,39–41,43]
>10 years	3 (13)	[25,26,35]
Not specified	5 (22)	[23,24,27,29,42]
Year of publication		
Before 2000	5 (22)	[28,30,31,33,38]

Table 2. continued

Characteristic	N (%)	References
2000–2005	11 (48)	[22,23,26,27,29,34,39–43]
2006–2010	4 (17)	[24,25,36,44]
2011–2014	3 (13)	[32,35,37]

*Questionnaire that intends to assess psychosocial impact or quality of life in a variety of populations or for a variety of conditions.

†Questionnaire that is specifically designed for the purpose of measuring psychosocial impact or quality of life in living organ donors or transplant recipients.

Social functioning (n = 5): In one study, donors experienced an increased awareness of how communities should function, including hospital, neighborhood, workplace, and friendship. They were grateful for the professional and non-professional support received and wanted to give back to the community [35]. In other studies, by contrast, donors complained about a lack of emotional support provided [33,38–40] and felt like they had been treated as ‘nonpatients’ by the medical team, as the staff’s attention seemed to focus on the recipient [39,40].

Impact on family

Donor–recipient relationship (n = 13): The donor–recipient relationship was affected in five main ways. First, an overall improved relationship was reported by donors [29,32–36,38,41,42], recipients [26,28,30,42,43], as well as nondonor parents [33,41]. Donors described a special bond between themselves and the recipient [35,42], which was referred to as a ‘region of intimacy’ [42] based on mutual admiration. Correspondingly, recipients sometimes referred to their fathers (the donors) as ‘buddies’ [42].

Second, transplantation evoked feelings of gratitude in recipients toward the donor. Several donors mentioned positive aspects of gratitude, for instance by receiving drawings of love or help from the recipients with chores [34,42]. Sometimes, though, feelings of gratitude induced distress in the recipients or hampered the process of becoming independent from their parents because of ambivalent feelings toward the donor. More specifically, some recipients felt grateful or guilty for having received an organ, while at the same time feeling angry about their parents’ overprotective or authoritarian attitude [28–30].

Third, transplantation raised new expectations in donors about recipients’ lifestyle, for instance by expecting them to change their drinking behavior [34].

Fourth, the donor–recipient relationship was negatively affected if the parents did not consider the child as the owner of the donated organ. However, only two such cases

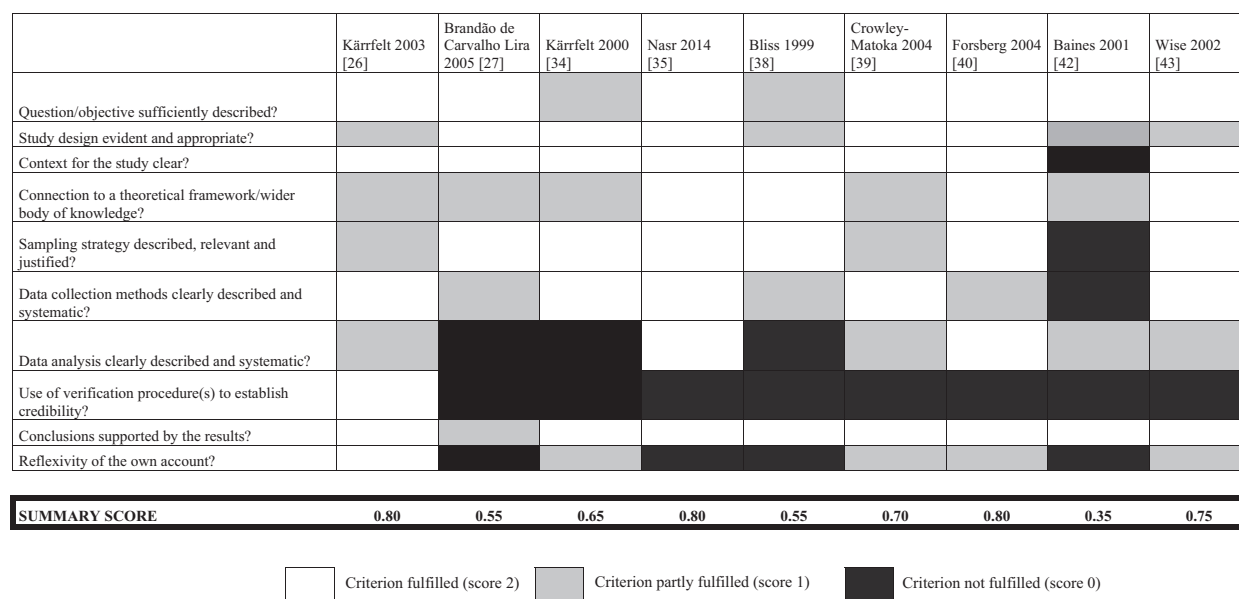


Figure 3 Quality of reporting of qualitative and mixed-methods studies.

were identified [34,41]. Correspondingly, recipients described their role as being a custodian, feeling grateful for the responsibility that the donor had entrusted them [42].

Fifth, fantasies about the donor played an important role in the coping process of pediatric recipients, especially at young age [26,34,43]. In one study, a young child thought he had to give his kidney 'in return' to the donor [34]. Another study described how a transplanted girl projected her own fear of needles onto her father, and thought that he could not receive vaccinations because she was unable to [43].

Relationship between donor and partner (n = 6): Many donors and partners reported an improved relationship [35,39,41], as priorities could be refocused on the family after donation [39]. Partners overall remained supportive of the donor's decision [29,41]. However, marital problems were reported as well [29,31,32,35,39] and were sometimes related to feelings of resentment in nondonor parents who felt a lack of appreciation for their caring role [35] or to distress caused by the transition to normal life after transplantation [39].

Relationship between donor and siblings (n = 5): In two studies, most donors reported no change in the relationship with other siblings [33,41]. In contrast, one study found that donors were sometimes concerned about the long-term impact on other siblings, particularly as parents' attention had been focused on the recipient for a long time

[39]. Another study concluded that parents of families with other children felt more alone in caring for their children and had less confidence in their caring capacities compared with families without siblings [44]. Furthermore, in one study, 90% of siblings had psychosocial difficulties, although these were not further specified [29].

Discussion

Our systematic review revealed a mixed picture of favorable and unfavorable psychosocial consequences of pediatric living-donor kidney and liver transplantation on recipients, donors, and the family. Although most recipients had few emotional difficulties and experienced improved coping skills and satisfactory peer relationships, some suffered from anxiety, distress, or depressive symptoms, worried about the future, and had a negative body image. In three studies, these unfavorable outcomes were related to problems in the relationship with the donor, characterized by guilt and indebtedness [28–30]. We speculate that these relationship problems are related to disturbed gift exchange dynamics. Indeed, the implicit obligation of reciprocity, which is characteristic of Marcel Mauss' theory of gift-giving, seems to be underlying as well the relationship between a transplanted child and his donor. Specifically, donors had new expectations about the recipient's lifestyle, and recipients attempted to comply with the obligation of reciprocity by providing drawings of love or by helping the donor with chores [34,42]. Moreover, our findings suggest that feelings of gratitude and admiration are frequently occurring in recipients and play an ambivalent role in their relationship

	Fukunishi 2001 [22]	Fukunishi 2002 [23]	Berney- Martinet 2009 [24]	El- Husseini 2010 [25]	Tisza 1976 [28]	Schulz 2001 [29]	Starkman 1980 [30]	Goldman 1993 [31]	Gökçe 2011 [32]	Kärrfelt 1998 [33]	Kroencke 2006 [36]	Kroencke 2014 [37]	Neuhaus 2005 [41]	Yoshino 2007 [44]
Question/objective sufficiently described?														
Study design evident and appropriate?														
Method of subject/comparison group selection or source of information/input variables described and appropriate?														
Subject (and comparison group) characteristics sufficiently described?														
Interventional and random allocation described?														
Interventional and blinding of investigators reported?														
Interventional and blinding of subjects reported?														
Outcome and exposure measure(s) well defined and robust to measurement. Means of assessment reported?														
Sample size appropriate?														
Analytic methods described/justified and appropriate?														
Some estimate of variance is reported for the main results?														
Controlled for confounding?														
Results reported in sufficient detail?														
Conclusions supported by the results?														
SUMMARY SCORE	0.55	0.13	0.86	0.59	0.60	0.32	1.00	0.50	0.81	0.59	0.68	0.90	0.82	0.73

	Criterion fulfilled (score 2)		Criterion partly fulfilled (score 1)		Criterion not fulfilled (score 0)		Criterion not applicable
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Figure 4 Quality of reporting of quantitative studies and descriptive case series.

with the donor. On the one hand, they seem to create a special bond between donor and recipient, which was characterized in one study as a 'region of intimacy' [42]. This might indicate an identification process, in which a recipient idealizes the donor and might even incorporate certain of his psychological or social characteristics [45]. On the other hand, if recipients feel unable to ever sufficiently 'give back' to the donor, gratitude might invoke distress and result in guilt or indebtedness. Consequently, although being a normal process when accepting an organ, identification should remain limited in scope and time, to allow the recipient to successfully develop an own identity.

Several aspects deserve further scrutiny. First, although donor and recipient outcomes seem inherently related, we identified only three studies that reported both donor and recipient outcomes [22,29,42]. To better understand the interaction between donors and recipients, enrolling both the donor and the recipient in the same study seems of utmost importance.

Second, as we hypothesize that gift exchange dynamics may persist even years after transplantation, more truly long-term perspectives on psychosocial impact seem warranted, as only three studies assessed psychosocial impact after more than ten years [25,26,35].

Third, it remains uncertain whether psychosocial impact is affected by recipients' age at the time of transplantation. Indeed, our findings suggest that even very young children might be confronted with an obligation to give back, as some had phantasies about 'returning the kidney to the donor' [26]. However, only four studies included both pediatric (0–12 years) and adolescent recipients (12–18 years), and none of them systematically assessed differences between these age groups. This is unfortunate: as younger patients might be less involved in the decision-making and less aware of the potential psychosocial consequences, we hypothesize that a disturbed gift relationship (for instance indebtedness or ambivalence toward the donor) might be more likely to occur in patients who were younger at the time of the transplant. This needs to be explored further.

Fourth, the large heterogeneity of indicators that were used across studies might indicate a lack of consensus about the appropriate manner to assess psychosocial outcomes in pediatric transplant recipients and their donors. Consequently, comparison of outcomes across studies was only possible to a limited extent. In addition, the appropriateness of some indicators that were used is questionable. For instance, the fact that nearly all donors would be willing to

donate again [29,32,36] might not necessarily indicate that donors and recipients cope well, but could also be related to parental feelings of responsibility to do whatever is in their power to take care for their children [9]. Consequently, a more adequate and systematic approach to assess psychosocial impact should be developed.

To address these shortcomings, we recommend more research on how gift dynamics affect the long-term relationship between donor and recipient. We hypothesize that prospective studies, using a qualitative approach that would combine data from interviews and observations, are particularly adequate to address the complexity of these dynamics. Indeed, qualitative methods would allow donors and recipients to address narratives and issues they believe to be important themselves to characterize their relationship, within their own language and from their own context. Moreover, using a dyadic interview technique (including donor and recipient within one interview), more light might be shed on the collective experience and shared understandings of the transplantation, adjustment, and self-care processes [46]. Furthermore, interviews about the psychosocial impact of transplantation have been successfully performed with adolescents as well as younger children [43], indicating that the latter are able to give valuable information about themselves and other family members. Specific examples of leading questions could be the following: Is the donor–recipient relationship characterized by implicit feelings of obligations and how do donors and recipients cope with these? To what extent is their relationship characterized by identification processes? How does transplantation impact the recipient's ability to achieve an identity of his own? How and when do families communicate about the transplantation and how are responsibilities concerning the recipient's health and adherence managed within the family?

Our study is subject to some potential limitations. First, we might have missed some studies that are relevant to the purpose of our study, despite our systematic approach and use of different sources to identify relevant papers. Second, we were unable to identify differences in psychosocial outcome between kidney and liver transplantation, given that donor outcomes were predominantly studied in the context of liver transplantation, whereas recipient outcomes in the context of kidney transplantation. Third, we were not able to differentiate study results with respect to quality of reporting, although we are aware that this was variable among studies.

Implications for practice

The findings of our systematic review may assist transplant professionals in supporting the adjustment process of families experiencing living-donor kidney and liver

transplantation and to identify or anticipate potential adverse psychosocial effects in donors or recipients. Transplant professionals should be aware that psychosocial outcomes of donors and recipients cannot be seen in isolation from how transplantation affects relationships within the family, for instance by raising mutual feelings of reciprocity in donors and recipients. This awareness is particularly important, given that some families tend to maintain a 'pact of silence' about these relational aspects to protect the recipient from potential negative feelings toward the donor, like guilt or indebtedness [47]. We believe there is a vital role for transplant professionals in detecting and abolishing these mechanisms of silence by encouraging donors and recipients to openly discuss family aspects with each other and with the healthcare team.

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References

1. Austin M, Feurer I, Chari R, Gorden D, Wright J, Pincon C. Survival after pediatric liver transplantation. Why does living donation offer an advantage? *Arch Surg* 2005; **140**: 465.
2. Cransberg K, Smits JMA, Offner G, Nauta J, Persijn GG. Kidney transplantation without prior dialysis in children: the eurotransplant experience. *Am J Transplant* 2006; **6**: 1858.
3. McKiernan PJ. Long-term care following paediatric liver transplantation. *Arch Dis Child Educ Pract Ed* 2011; **96**: 82.
4. Burra P, De Bona M. Quality of life following organ transplantation. *Transpl Int* 2007; **20**: 397.
5. Simons LE, Anglin G, Warshaw BL, Mahle WT, Vincent RN, Blount RL. Understanding the pathway between the transplant experience and health-related quality of life outcomes in adolescents. *Pediatr Transplant* 2008; **12**: 187.
6. Tong A, Morton R, Howard K, Craig JC. Adolescent experiences following organ transplantation: a systematic review of qualitative studies. *J Pediatr* 2009; **155**: 542.
7. Gerson AC, Furth SL, Neu AM, Fivush BA. Assessing associations between medication adherence and potentially modifiable psychosocial variables in pediatric kidney transplant recipients and their families. *Pediatr Transplant* 2004; **8**: 543.
8. Mauss M. Essai sur le don. Forme et raison de l'échange dans les sociétés archaïques. In: *Sociologie et anthropologie*.

- Paris: Les Presses universitaires de France, 1968 (4th ed.); 482 pp.
9. Zeiler K, Guntram L, Lennerling A. Moral tales of parental living kidney donation: a parenthood moral imperative and its relevance for decision making. *Med Health Care Philos* 2010; **13**: 225.
 10. Franklin PM, Crombie AK. Live related renal transplantation: psychological, social, and cultural issues. *Transplantation* 2003; **76**: 1247.
 11. Schwering K-L, Aujoulat I. Gift dynamics and identity construction within the family. In: Weimar W, Bos M, Busschbach J, eds. *Organ Transplantation, Ethical, Legal and Psychosocial Aspects*. Lengerich: Pabst Science Publishers, 2014: 181.
 12. Tong A, Chapman JR, Wong G, Kanellis J, McCarthy G, Craig JC. The motivations and experiences of living kidney donors: a thematic synthesis. *Am J Kidney Dis* 2012; **60**: 15.
 13. Chen PX, Yan LN. Health-related quality of life in living liver donors after transplantation. *Hepatobiliary Pancreat Dis Int* 2011; **10**: 356.
 14. Gill P, Lowes L. Gift exchange and organ donation: donor and recipient experiences of live related kidney transplantation. *Int J Nurs Stud* 2008; **45**: 1607.
 15. Crombie AK, Franklin PM. Family issues implicit in living donation. *Mortality* 2006; **11**: 196.
 16. Aujoulat I, Schwering KL, Reding R. Living-related donation: a challenge to adolescent transplant recipients who transit from parental care to self-managed care. *Child Care Health Dev* 2012; **38**: 146.
 17. Aujoulat I, Janssen M, Libion F, et al. Internalizing motivation to self-care: a multifaceted challenge for young liver transplant recipients. *Qual Health Res* 2014; **24**: 357.
 18. Fennell RS, Tucker C, Pedersen T. Demographic and medical predictors of medication compliance among ethnically different pediatric renal transplant patients. *Pediatr Transplant* 2001; **5**: 343.
 19. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the prisma statement. *BMJ* 2009; **339**: b2535.
 20. Kmet L, Lee R, Cook L. Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields. Alberta Heritage Foundation for Medical Research, 2004. Available at <http://www.ihe.ca/documents/HTA-FR13.pdf> (last accessed 4 April 2014).
 21. Duerinckx N, Timmerman L, Van Gogh J, et al. Predonation psychosocial evaluation of living kidney and liver donor candidates: a systematic literature review. *Transpl Int* 2014; **27**: 2.
 22. Fukunishi I, Sugawara Y, Takayama T, Makuuchi M, Kawarasaki H, Surman OS. Psychiatric disorders before and after living-related transplantation. *Psychosomatics* 2001; **42**: 337.
 23. Fukunishi I, Sugawara Y, Takayama T, et al. Maladjustment behaviors in pediatric living-related transplantation. *Transplant Proc* 2002; **34**: 2767.
 24. Berney-Martinet S, Key F, Bell L, Lépine S, Clermont MJ, Fombonne E. Psychological profile of adolescents with a kidney transplant. *Pediatr Transplant* 2009; **13**: 701.
 25. El-Husseini A, Hassan R, Sobh M, Ghoneim M. The effects of gender on health-related quality of life in pediatric live-donor kidney transplantation: a single-center experience in a developing country. *Pediatr Transplant* 2010; **14**: 188.
 26. Kärrfelt HME, Lindblad FIE, Crafoord J, Berg UB. Renal transplantation: long-term adaptation and the children's own reflections. *Pediatr Transplant* 2003; **7**: 69.
 27. Brandão de Carvalho Lira AL, Vilani Cavalcante Guedes M, Venícios de Oliveira Lopes M. Adolescente Renal Crônico: Alterações Físicas, Sociais y Emocionales Pos-Transplante. *Rev Soc Esp Enferm Nefrol* 2005; **8**: 260.
 28. Tisza VB, Dorsett P, Morse J. Psychological implications of renal transplantation. *J Am Acad Child Psychiatry* 1976; **15**: 709.
 29. Schulz K, Hofmann C, Sander K, Edsen S, Burdelski M, Rogiers X. Comparison of quality of life and family stress in families of children with living-related liver transplants versus families of children who received a cadaveric liver. *Transplant Proc* 2001; **33**: 1496.
 30. Starkman MN. Psychological problems resulting from renal transplantation. *Gen Hosp Psychiatry* 1980; **2**: 289.
 31. Goldman LS. Liver transplantation using living donors. Preliminary Donor Psychiatric Outcomes. *Psychosomatics* 1993; **34**: 235.
 32. Gökçe S, Durmaz Ö, Peykerli Gürsu G, et al. Assessment of living donors with respect to pre- and posttransplant psychosocial properties and posttransplant family functioning in pediatric liver transplantation. *Turk J Gastroenterol* 2011; **22**: 36.
 33. Kärrfelt HM, Berg UB, Lindblad FIE, Tydén GE. To be or not to be a living donor: questionnaire to parents of children who have undergone renal transplantation. *Transplantation* 1998; **65**: 915.
 34. Kärrfelt HM, Berg UB, Lindblad FI. Renal transplantation in children: psychological and donation-related aspects from the parental perspective. *Pediatr Transplant* 2000; **4**: 305.
 35. Nasr AS, Rehm RS. Parental live liver donation: a transformational experience. *Prog Transplant* 2014; **24**: 69.
 36. Kroencke S, Wilms C, Broering D, Rogiers X, Schulz K. Psychosocial aspects of pediatric living donor. *Liver Transpl* 2006; **12**: 1661.
 37. Kroencke S, Nashan B, Lutz F, Erim Y, Schulz KH. Donor quality of life up to two years after living donor liver transplantation: a prospective study. *Transplantation* 2014; **97**: 582.
 38. Bliss A, Stuber ML. Giving life for the second time: a preliminary study of parental partial liver donation for pediatric transplantation. *Fam Syst Health* 1999; **17**: 217.
 39. Crowley-Matoka M, Siegler M, Cronin DC. Long-term quality of life issues among adult-to-pediatric living liver donors: a qualitative exploration. *Am J Transplant* 2004; **4**: 744.

40. Forsberg A, Nilsson M, Krantz M, Olausson M. The essence of living parental liver donation: donors' lived experiences of donation to their children. *Pediatr Transplant* 2004; **8**: 372.
41. Neuhaus TJ, Wartmann M, Weber M, Landolt MA, Laube GF, Kemper MJ. Psychosocial impact of living-related kidney transplantation on donors and partners. *Pediatr Nephrol* 2005; **20**: 205.
42. Baines LS, Beattie TJ, Murphy AV, Jindal RM. Relationship between donors and pediatric recipients of kidney transplants: a psychosocial study. *Transplant Proc* 2001; **33**: 1897.
43. Wise BV. In their own words: the lived experience of pediatric liver transplantation. *Qual Health Res* 2002; **12**: 74.
44. Yoshino M, Yoshino H, Kusano A, Mizuta K, Kawarasaki H. The influence of living donor liver transplantation on families with or without siblings. *Pediatr Transplant* 2007; **11**: 624.
45. Goetzmann L, Irani S, Moser KS, et al. Psychological processing of transplantation in lung recipients : a quantitative study of organ integration and the relationship to the donor. *Br J Health Psychol* 2009; **14**: 667.
46. Taylor B, De Vocht H. Interviewing separately or as couples? Considerations of authenticity of method. *Qual Health Res* 2011; **21**: 1576.
47. Scheper-Hughes N. The tyranny of the gift: sacrificial violence in living donor transplants. *Am J Transplant* 2007; **7**: 507.